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MURDER, SHE WROTE OR WAS IT MERELY SELECTIVE NONTREATMENT?

George P. Smith, II*

INTRODUCTION

It has been estimated conservatively that the number of cases each year of severely handicapped infants being denied life-saving medical treatment is approximately 5000;¹ this estimate is derived from a raw statistic from The National Center for Health Statistics revealing that 140,000 babies were born suffering from some type of physical abnormality, mental retardation, or learning disability.² Another source estimates that one out of every twenty babies is born with some type of discernible genetic deficiency³ and that of all chronic diseases, between twenty and twenty-five percent are

* B.S., J.D., Indiana University; LL.M., Columbia University; Professor of Law, Catholic University of America.

1. See Carlton Sherwood, *'Baby Doe' is Dividing the Medical Community*, WASH. TIMES, July 9, 1984, at 5A.

2. Don Colburn, *Birth Defects Kill 8,000 American Infants Each Year*, WASH. POST, Dec. 17, 1991, Health Magazine, at 5; Richard D. Lyons, *Physical and Mental Disabilities in Newborns Doubled in 25 Years*, N.Y. TIMES, July 18, 1983, at A1. The March of Dimes Birth Defects Association reported recently that in the United States each year birth defects are the cause of death of more than 8,000 babies less than one year old; Colburn, *supra*, at 5. Some 250,000 babies in America are born each year—or approximately 1 in every 16—with birth defects ranging from heart problems to respiratory distress and spinal cord abnormalities. *Id.* In addition to these birth defects, another major cause of infant mortality is low birthweight. *Id.* See also T.S. Ellis, III, *Letting Defective Babies Die: Who Decides?*, 7 AM. J.L. & MED. 393, 393 n.1 (1982). Actual verification is very difficult; thus, the reliability of research data regarding the incidence of nontreatment is both scant and subject to serious dispute.

In a 1973 study by Duff and Campbell of 299 consecutive deaths in a special care nursery, 43 (or 14%) were found to be related to the withholding of treatment. See Raymond S. Duff & A.G.M. Campbell, *Moral and Ethical Dilemmas: Seven Years into the Debate About Human Ambiguity*, 477 ANNALS AM. ACAD. POL. & SOC. SCI. 19, 19 (1980). For an analysis of their previous study, see *infra* note 7 and accompanying text. If extrapolated to a national figure and then multiplied by the number of newborn intensive care nurseries extant in 1973, the data would show that several thousand infants a year would not be treated. H. Rutherford Turnbull, III, *Incidence of Infanticide in America: Public and Professional Attitudes*, 1 ISSUES L. & MED. 363, 379 nn.89-90 (1986) (citing Michael L. Hardman, *The Role of Congress in Decisions Relating to the Withholding of Medical Treatment from Seriously Ill Newborns*, 9 J. ASSOC. FOR PERSONS WITH SEVERE HANDICAPS 3, 3 (1984)).

3. Roderic Gorney, *The New Biology and the Future of Man*, 15 UCLA L. REV. 273, 291 (1968).

predominantly genetic in origin.⁴

In 1973, nine years before the famous Baby Doe case in Bloomington, Indiana, that began on April 8, 1982 and ended six days later, and in turn sparked the federal government's efforts to re-interpret Section 504 of the Federal Rehabilitation Act⁵ to prevent withholding of life-saving treatment from handicapped or defective newborns,⁶ Yale New-Haven Hospital released a startling study of special care nursing treatment of neonates that showed that 14% of the 299 deaths recorded during the period of the study—eighteen months—were related to actions which withheld treatment.⁷ The publication of this study initiated a public dialogue and raised issues regarding the treatment of defective newborns or neonates which previously had been raised privately by attending physicians, with or without familial consultation.⁸

In 1975, questionnaires were sent to all members of the Surgical Section of the American Association of Pediatricians, to all chairpersons of teaching departments of pediatrics in the United States, and to chiefs of neonatology divisions and genetic divisions in pediatric departments. Two hundred sixty-seven physicians from the members and chairpersons and one hundred ninety-seven from the division chiefs returned completed questionnaires. The results showed "broad support" for the propositions that: physicians need not attempt to maintain the life of every severely impaired newborn simply because the technology and skill existed; parents and physicians (in that order) bear the ultimate responsibility for making decisions regarding the withholding or administration of treatment for severely handicapped newborns; such decisions should be made on the basis of the best medical predictions regarding longevity and the child's quality of life; under certain "egregious" circumstances physicians could seek judicial intervention to effectuate treatment; and, finally, decisions to treat or not to treat defective

4. Arthur Robinson, *Genetics and Society*, 1971 UTAH L. REV. 487, 487.

5. 29 U.S.C. § 794 (1982).

After investigating some 49 incidents of alleged discrimination in the withholding of medical treatment during the few months it was charged with enforcing the Baby Doe regulations under Section 504, the Department of Health and Human Services found no provable cases of discrimination. Turnbull, *supra* note 2, at 382. See generally Phillip H. Snelling, *Discrimination Against Children with Special Health Care Needs: Title V Crippled Children's Services Programs and Section 504 of the Rehabilitation Act of 1973*, 18 LOY. U. CHI. L.J. 995 (1987).

6. George P. Smith, II, *Quality of Life, Sanctity of Creation: Palliative or Apotheosis?*, 63 NEB. L. REV. 709, 729 *passim* (1984).

7. Raymond S. Duff & A.G.M. Campbell, *Moral and Ethical Dilemmas in the Special Care Nursery*, 289 NEW. ENG. J. MED. 890, 891 (1973).

8. Ellis, *supra* note 2, at 399. See generally John A. Robertson, *Involuntary Euthanasia of Defective Newborns: A Legal Analysis*, 27 STAN. L. REV. 213 (1975).

newborns were best made on a "case-by-case" or situational basis.⁹

The majority of the members of the medical profession are of the opinion that the autonomy of the parent-physician relationship should be maintained in this critical area of concern.¹⁰ It is submitted that the affected or involved physicians and the families to which they attend are the most informed parties in a case involving treatment or nontreatment decisions of handicapped, at-risk newborns and that they should be accorded both respect and latitude in making these necessary decisions.¹¹ There is another school of thought among physicians which maintains that parents—traumatized emotionally by the birth of a defective child—are in no position to make life or death treatment decisions on its behalf.¹² Finally, while serving as the Surgeon General of the United States, C. Everett Koop asserted that decisions to withhold treatment for handicapped newborns are acts of "infanticide."¹³ He opposes the exclusive reliance that is placed upon the precincts of the physician-parent autonomy in this area of concern.¹⁴

This article will both explore and thereby establish the medical, ethical, and legal validity of selective nontreatment of severely handicapped newborns. A construct for principled decision-making, tied to a basic recognition of the right of self-determination, as shaped by compassion and validated principles of *triage* and cost-benefit analysis, will be seen as the most effective means for the states—and not the federal government—to evaluate the intensely complex issues associated with allocating scarce medical resources to defective infants. Governmental intrusions into the familial decision-making forum in these circumstances must be kept to a minimum and allowed only in grave cases.

9. MICHAEL H. SHAPIRO & ROY G. SPECE, JR., CASES, MATERIALS AND PROBLEMS ON BIOETHICS AND LAW 702, 702-03 (1981). For a presentation of the differing views within the medical profession on the treatment of a newborn with serious birth defects, see generally Benjy F. Brooks, *Ethical Dilemmas in The Treatment of Critically Ill Newborns*, 1 J. CONTEMP. HEALTH L. & POL'Y 133 (1985).

10. Duff & Campbell, *supra* note 7. See generally Harvard, *Legislation is Likely to Create More Difficulties than It Resolves*, 9 J. MED. ETHICS 18 (1983).

11. Duff & Campbell, *supra* note 7, at 893-94.

12. Norman Fost, *Counseling Families Who Have a Child with a Severe Congenital Anomaly*, 67 PEDIATRICS 321, 322-23 (1981); Eugene F. Diamond, *Treatment Versus Nontreatment for the Handicapped Newborn*, in INFANTICIDE AND THE HANDICAPPED NEWBORN 55, 62 (Dennis J. Horan & Melinda Delahoyde eds., 1982) [hereinafter INFANTICIDE].

13. C. Everett Koop, *Ethical and Surgical Considerations in the Care of the Newborn with Congenital Abnormalities*, in INFANTICIDE, *supra* note 12, at 90.

14. *Id.*

I. ADMINISTRATIVE DETERMINATIONS AND ETHICAL DILEMMAS

The President's Commission

In a 1983 report, the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research critically examined governmental intrusions into the parent-physician decision-making process.¹⁵ The Commission concluded that an approach should be followed which recognizes that the nontreatment of genetically defective newborns is subject to explicit hospital policies and that such decisions may be made by the concerned parents with the advice of an attending or consulting physician and without the threat of federal sanctions against the hospital.¹⁶ The Commission urged that the entire process of decision-making be opened to include the formation of ethic review committees and that their deliberations be considered—in order to assure an objective assessment—in those cases where the most complexity and difficulty exist.¹⁷ Thus, by the establishment of an internal review process, judicial intervention would be obviated and only permissible when a “rapidly deteriorating medical status” of a handicapped newborn requires parents and physicians alike to act without this internal review.¹⁸

The American Medical Association Speaks

The American Medical Association's Judicial Council reached a similar conclusion to that of the President's Commission. More specifically, the Council put forth the proposition that as to quality of life decisions affecting the treatment of seriously deformed infants,

the primary consideration should be what is best for the individual patient and not the avoidance of a burden to the family or to society. Quality of life is a factor to be considered in determining what is best for the individual. Life should be cherished despite disabilities and handicaps, except when the prolongation would be *inhuman* and *unconscionable*. Under these circumstances, withholding or removing life supporting means is ethical provided that the normal care given an individual who is ill is not discontinued. *In desperate situations involving newborns, the advice and judgment of the physician should be readily available, but the deci-*

15. PRESIDENT'S COMMISSION FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH, DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT: A REPORT ON ETHICAL, MEDICAL AND LEGAL ISSUES IN TREATMENT DECISIONS (1983). This Commission ceased operating in 1983.

16. *Id.* at 226-27.

17. *Id.* at 227.

18. *Id.* at 228.

sion whether to exert maximal efforts to sustain life should be the choice of the parents. The parents should be told the options, expected benefits, risks and limits of any proposed care; how the potential for human relationships is affected by the infant's condition; and relevant information and answers to their questions. The presumption is that the love which parents usually have for their children will be dominant in the decisions which they make in determining what is in the best interest of their children. It is to be expected that parents will act unselfishly, particularly where life itself is at stake. Unless there is convincing evidence to the contrary, parental authority should be respected.¹⁹

Further Amplification by the AMA

On March 15, 1986, the Council on Ethical and Judicial Affairs issued a policy on withholding or withdrawing life prolonging medical treatment²⁰ which will affect the estimated ten thousand people who are in irreversible comas in institutions around the country.²¹ In essence, this policy statement maintains that it is ethical for physicians to withhold "all means of life prolonging medical treatment" including water, from patients in irreversible comas. While recognizing the social commitment of the physician to sustain life and relieve suffering, the Council advises that, "[w]here the performance of one duty conflicts with the other, . . . the physician must act in the best interest of the patient."²² Thus, in following a course of treatment for a terminally ill or irreversibly comatose patient, the physician should determine whether the benefits of treatment outweigh its burdens and seek to maintain the dignity of the patient at all times.²³

The Council states that, "[f]or humane reasons, with informed consent, a physician may do what is medically necessary to alleviate severe pain, or cease or omit treatment to permit a terminally ill patient whose death is imminent to die. However, he should not intentionally cause death."²⁴ In making decisions whether the administration of potentially life-prolonging

19. COUNCIL ON ETHICAL AND JUDICIAL AFFAIRS, AM. MED. ASS'N, CURRENT OPINIONS 9 (1982) (emphasis added). For a discussion of decision-making for incompetents of all ages and mental capacities in both the medical and nonmedical setting, see generally ALLEN E. BUCHANAN & DAN W. BROCK, *DECIDING FOR OTHERS: THE ETHICS OF SURROGATE DECISION MAKING* (1989).

20. COUNCIL ON ETHICAL AND JUDICIAL AFFAIRS, AM. MED. ASS'N, CURRENT OPINIONS 12-13 (1986) [hereinafter *CURRENT OPINIONS* 1986].

21. Andrew H. Malcolm, *A.M.A. Rule: Step Toward a Social Policy on Dying*, N.Y. TIMES, Mar. 17, 1986, at B7.

22. *CURRENT OPINIONS* 1986, *supra* note 20, at 12.

23. *Id.* at 13.

24. *Id.* at 12.

medical treatment comports with the best interests of an incompetent patient who is unable to act in his own behalf, the physician should determine what the possibility is for extending life under humane and comfortable conditions. A further determination should be made as to the prior expressed wishes of the patient and attitudes of the family or those who have responsibility for the custody. According to the policy, it is not unethical to discontinue all means of life-prolonging treatment when the patient's coma is undoubtedly irreversible, death is not imminent, there are sufficient methods of confirming the accuracy of the diagnosis, and the treating physician concurs.²⁵

A Canadian Approach

Interestingly, the Law Reform Commission of Canada has reported that decisions to treat or not to treat defective newborns should be made according to the medical facts of each case, on a reasonable basis, in the best interests of the patient, and in conformity with pertinent standards set out by criminal law.²⁶ Acceptable quality of life is essentially a question of facts which differ in each case.²⁷ Yet it is also a question of sound medical judgment based in turn upon medical experience as well as consultation with the concerned party or parties such as parents, spouse, family, and next of kin.²⁸

Philosophical Concerns

Fr. Richard A. McCormick has observed that while every *person* is of "equal value," not every *life* is.²⁹ He suggests that if life is regarded as "the continuation of vital processes but in a persistent vegetative state; if 'value' means 'a good to the individual concerned'; if 'equal' means 'identical' or the 'same,' especially of treatment, then . . . it is . . . false to say that 'every life is of equal value.'"³⁰ He suggests that what the "equal value" language connotes is that unjust discrimination in the provision of health care and life-supports should be avoided.³¹ Not all discrimination or unequal treatment,

25. *Id.* at 12-13.

26. LAW REFORM COMM'N OF CANADA, REPORT 20, EUTHANASIA, AIDING SUICIDE AND CESSATION OF TREATMENT 24-25 (1983).

27. *Id.* at 24.

28. *Id.* at 24-25. See generally George P. Smith, II, *The Plight of the Genetically Handicapped Newborn: A Comparative Analysis*, 9 *HOLDSWORTH L. REV.* 164 (1984).

29. Richard A. McCormick, *The Quality of Life, The Sanctity of Life*, HASTINGS CENTER REP., Feb. 1978, at 30, 35.

30. *Id.*

31. *Id.* For a thorough discussion of the need for an unfettered moral and legal right of all competent persons to refuse life-sustaining medical treatment, see GEORGE P. SMITH, II, *FINAL CHOICES: AUTONOMY IN HEALTH CARE DECISIONS* (1989).

however, is unjust.³² To avoid unjust discrimination, critical decision-making should center upon the benefits to the patient even if the particular benefit must be described primarily in terms of a quality-of-life criteria.³³

Dr. Tristram Engelhardt has synthesized with cogent clarity the central concern in selective non-treatment by stating that it would be reasonable to suggest (or even advocate) that when a child suffers from a disease which brings uncontrolled levels of pain and no hope of survival, life should not be prolonged by means of extraordinary medical measures, nor should the injury of continued existence be allowed.³⁴

There is a time when it is proper to acknowledge that death is not the greatest evil and, thus, to "acquiesce in its victory."³⁵ While there is a duty to preserve life, recognition must be made of the fact that death is the door to eternal life.³⁶ And it can be wrong for physicians, as well as the family unit, to turn the very process of dying into a "technological circus."³⁷ This is, of course, not a depreciation of the sanctity of life. Rather, it recognizes that death must come and that at some point in time extreme measures of resistance are neither necessary nor appropriate.³⁸

II. INDICATORS OF QUALITATIVE LIVING

Social Justice

Social justice demands that each individual be given an opportunity to maximize his individual potential.³⁹ Often a point is reached where maintenance of an individual is in defiance of all concepts of basic humanitarianism

32. McCormick, *supra* note 29, at 35. See generally HELGA KUHSE, *THE SANCTITY-OF-LIFE DOCTRINE IN MEDICINE* (1987) (maintaining that decisions to withhold life-sustaining treatment should not be based upon spurious classifications of such treatment as "extraordinary," "not medically indicated," or "disproportionately burdensome," but upon a soundly based "quality of life ethic" which considers the fact that not all life is of equal value to the possessor).

33. McCormick, *supra* note 29, at 35.

34. H. Tristram Engelhardt, Jr., *Ethical Issues in Aiding the Death of Young Children*, in *BENEFICENT EUTHANASIA* 180, 187 (Marvin Kohl ed., 1975); H. Tristram Engelhardt, Jr., *Euthanasia and Children: The Injury of Continued Existence*, 83 J. PEDIATRICS 170, 171 (1973).

35. CHARLES E. RICE, *BEYOND ABORTION: THE THEORY AND PRACTICE OF THE SECULAR STATE* 119 (1979).

36. *Id.*

37. *Id.*

38. *Id.*; see also Malcolm, *supra* note 21, at B7 (reporting on the American Medical Association's determination that it would be ethical for doctors to withhold "all means of life prolonging medical treatment").

39. RICHARD A. MCCORMICK, *HOW BRAVE A NEW WORLD?: DILEMMAS IN BIOETHICS* 349 (1981).

and social justice.⁴⁰ When an individual's condition is such that it lacks any "truly human" qualities or "relational potential," the best form of treatment should be no treatment at all.⁴¹

A Potential for Relationship

Life should not be viewed as an end in and of itself, but rather as something that should be preserved so that other values can be fulfilled. Life should only be preserved when it holds a potentiality for human relationships.⁴² Although this standard does not admit of mathematical precision and must be applied with great humility and caution, it is nonetheless a beginning from which particular medical formulations may be developed.

Little disagreement is likely to be found with the conclusion that an anencephalic infant (one without a brain) has no "relational potential."⁴³ The same conclusions could not be said of an infant with Down's Syndrome.⁴⁴ In the final analysis, a "relational potential" test is needed which applies "to presumptive biological symptoms for the gray area between such extremes."⁴⁵ Even with this, however, the decisions will have to be made by the parents, relying on the integrity and professionalism of medical personnel.⁴⁶ If a grossly deformed infant enjoys no potential for developing or enjoying relationships with others, or if there is a potential but it would remain undeveloped in a basic struggle to survive, then it can be said that that infant's life has achieved its greatest potential.⁴⁷ Under these circumstances, it may be concluded that such an infant should be allowed to die. Since the condition of the infant is extraordinary, the means of treatment are, in turn, extraordinary and need not be used.⁴⁸

Love as a Decisional Force

If the binding force of life is love, then it can be argued that man should endeavor to maximize a response to love in whatever life situations man finds himself.⁴⁹ If an act renders more harm than good to the individual concerned and to those around him, the act would properly be viewed as

40. *Id.* at 348-49.

41. *Id.* at 349.

42. *Id.*

43. *Id.* at 350.

44. *Id.*

45. *Id.*

46. *Id.*

47. *Id.* at 349.

48. *Id.*

49. See generally Joseph Fletcher, *Love Is the Only Measure*, 83 COMMONWEAL 427 (1966) (asserting that love should be the factor in moral decision-making).

"unloving."⁵⁰ The crucial point of understanding is that a basic cost/benefit analysis is almost always consciously or unconsciously undertaken. Of course, the methodology utilized in this assessment will be situational and incapable of absolute determination.⁵¹ Of necessity, the basic norm or standard to be used will be love.

Moral obligations must arise from more than mere situations or consequences when the relationship is based on love, particularly a parent-child relationship. The measurement of a defective infant's potential for developing human relationships serves as a valuable and rational construct for determining the newborn's future. The "situational ethic of love" is complemented and magnified when engrafted onto the "relational potential" standard. While a person has a value of incalculable worth, there are situations in which continued physical existence offers no benefits. As such, to maintain "life" could well be regarded as an assault on the infant itself and on its very dignity.⁵²

Qualities of Humanhood

Dr. Joseph Fletcher has assembled a profile of fifteen qualities, attitudes, or indicators of humanhood. According to Dr. Fletcher, to be considered "human" a child must possess: minimal intelligence—those below a 20 I.Q. mark in a Stanford-Binet test are not considered persons; self-awareness; self-control; time consciousness; a sense of futurity tied to a teleological assertion; a sense of the past, or memory; a capability to relate to others; an ability to express concern for others; an ability to communicate; an ability to assert control over one's existence and not display utter helplessness; an ability to display curiosity instead of indifference; a capacity for changing one's mind; an ability to balance rationality with emotion and intuition; an ability to be idiomorphous or distinctive; and finally, a capacity for neo-cortical functions.⁵³ Dr. Fletcher especially stresses the importance of the infant's ability to use its brain: "[I]n the absence of the synthesizing function of the cerebral cortex, the *person* is non-existent. Such individuals are objects but not subjects Personal reality depends on cerebration and to be dead 'humanly' speaking is to be ex-cerebral, no matter how long the *body* re-

50. RICHARD A. MCCORMICK, NOTES ON MORAL THEOLOGY, 1965 THROUGH 1980 at 77 (1981).

51. *Id.*

52. MCCORMICK, *supra* note 39, at 396; see also Dick Thompson, *Should Every Baby Be Saved?*, TIME, June 11, 1980, at 81 (discussing the tremendous expenditures involved in treating premature infants).

53. Joseph Fletcher, *Indicators of Humanhood: A Tentative Profile of Man*, HASTINGS CENTER REP., Nov. 1972, at 1-3.

mains alive."⁵⁴ Dr. Fletcher's profile provides a compassionate and balanced test for determining the potential for sustaining human relationships. The deontological ethic thus merges creatively with the situation ethic.

III. STANDARDS OF SALVAGEABILITY

Birth Weights

Statistics indicate that American physicians tend to "salvage" infants weighing more than one and one-half pounds, but reject life-saving care for those newborns weighing less than this weight.⁵⁵ A recent report of infant births in the United States disclosed the fact that infants in the 501-750 gram range (1 lb. 1-1/2 oz. to 1 lb. 10-1/4 oz.) are oftentimes treated aggressively.⁵⁶ If an infant is born in the 751-1,000 gram range (1 lb. 10-1/4 oz. to 2 lb. 3 oz.), it is commonly treated in an aggressive manner, while an infant weighing more than 1,001 grams (2 lb. 3 oz.) at birth is routinely treated aggressively.⁵⁷

In contrast, intensive care in Britain and Sweden is generally reserved for infants over 750 grams.⁵⁸ Conversely, when an infant weighs less than 750 grams, it is seldom subjected to aggressive care.⁵⁹ As a consequence of this general policy, fewer disabilities result in British and Swedish infants of low birth-weight from aggressive treatment than in the United States.⁶⁰

An infant with a very low birth-weight is susceptible to brain injuries, which in turn may result in associated handicaps such as mental retardation

54. *Id.* at 3; see also George P. Smith, II, *Recognizing Personhood and the Right to Die with Dignity*, 6 J. PALLIATIVE CARE 24 (1990) (asserting that death cannot be viewed as either an event or a configuration since multiple parts of the body can continue to function long after the basic attributes or indicators of personhood are lost).

55. Ernle W.D. Young, *Caring for Disabled Infants*, HASTINGS CENTER REP., Aug. 1983, at 15; see also Carson Strong, *The Tiniest Newborns*, HASTINGS CENTER REP., Feb. 1983, at 14.

The average cost of care for the smallest premature infants at Stanford University Hospital was found recently to be approximately \$160,000, while nationally it was determined that \$2.6 billion is spent on neonatal intensive care each year. Ernle W.D. Young & David K. Stevenson, *Limiting Treatment for Extremely Premature, Low-Birth-Weight Infants (500 to 750 g)*, 144 AM. J. DISEASES CHILDREN 549, 549-50 (1990); see also Maureen Hack & Avroy A. Fanaroff, *Outcomes of Extremely-Low-Birth-Weight Infants Between 1982 and 1988*, 321 NEW. ENG. J. MED. 1642 (1989) (studying the survival rate of premature infants).

56. Young, *supra* note 55, at 15.

57. *Id.* The most common reason for low birth weight and premature delivery is lack of prenatal care. Abigail Trafford, *Scenes From an Intensive Care Nursery: Death is not the Worst Thing on the Unit at Children's National Medical Center*, WASH. POST, Apr. 2, 1991, Health Magazine, at 9.

58. Young, *supra* note 55, at 15.

59. *Id.*

60. *Id.*

and cerebral palsy; sustained treatment may only be obtained at considerable financial expense.⁶¹ It has therefore been suggested that a cut-off weight be set at 1,000 grams (about 2 lb., 3 oz.), below which aggressive treatment could be justifiably withheld.⁶² Another viable alternative would be to withhold aggressive infant care when a birth-weight of 1,000 grams or less is recorded for those born in a state of severe asphyxiation.⁶³

It should be emphasized that nonaggressive care does *not* mean "no care." Rather, it has been termed as "conservative care," and is recognized to be a less intensive mode of therapy designed to promote the newborn's comfort and well-being.⁶⁴ Nonaggressive care may be performed by maintaining the distressed infant's warmth, periodically providing fluids, and placing the infant under an oxygen hood in order to prevent cyanosis.⁶⁵

It should also be stressed that an infant's birth weight is only *one factor* to be weighed in the decision to withhold intensive treatment. Selective nontreatment should be administered on the basis of a determination, made by the family and its physicians, which would focus on a combination of factors such as the potential for quality of sustained life and economic considerations of cost-effectiveness in saving and promoting a particular life.⁶⁶

Genetic Profiles

Genetic factors are also frequently considered. The most commonly agreed upon genetic factors which justify the withholding or discontinuation of aggressive therapies are tied to severe abnormalities, diseases, or damage

61. Strong, *supra* note 55, at 14. There is significant medical uncertainty for the survival rate of low-weight infants, thus leading to drastically different treatments, particularly of newborns in the 500-750 gram range. Nancy K. Rhoden, *Treating Baby Doe: The Ethics of Uncertainty*, HASTINGS CENTER REP., Aug. 1986, at 34, 34-35. Indeed, there is really no way of knowing at the outset whether an infant of this nature will survive. Even with survival, it is still impossible to predict with accuracy whether it will be normal or either slightly or severely impaired. Young & Stevenson, *supra* note 55, at 549. Sadly, maternal substance abuse during pregnancy is all too often yet another reason for the high incidence of handicapped and low-birth-weight newborns. See generally George P. Smith, II, *Fetal Abuse: Culpable Behavior by Pregnant Women or Parental Immunity?*, 3 J.L. & HEALTH 23 (1988-89).

62. Strong, *supra* note 55, at 14-15.

63. *Id.* at 15.

64. *Id.*

65. *Id.*

66. *Id.* at 17; see also George P. Smith, II, *Death Be Not Proud: Medical, Ethical and Legal Dilemmas in Resource Allocation*, 3 J. CONTEMP. HEALTH L. & POL'Y 47 (1987) (asserting that life should be developed and preserved only if it achieves its fullest potential for total economic realization); Sandy Rovner, *Deciding the Fate of Premature Infants: Ethicists Explore the Dilemma of Keeping Very Frail Babies Alive*, WASH. POST, July 24, 1990, Health Magazine, at 11 (discussing the various treatments for low birth-weight babies given the high associated health care costs).

to an infant's central nervous system.⁶⁷ "Severe afflictions" would include cases of hydranencephaly, severe neural tube defects, gross hydrocephalus (if complicated by infection), and specific chromosomal disorders such as trisomy 13 and 18.⁶⁸

A vast array of surgical techniques can now preserve life for weeks or even months, in spite of severe defects. For example, prompt surgery can save children with spina bifida (exposure of the spinal cord) from death, but treatment rarely can save them from lives of partial paralysis, mental retardation, or a complete dependence upon others for assistance in performing the simplest body functions.⁶⁹ The lives of grossly premature infants who have severe cases of mental retardation (due to oxygen deprivation during birth) can also be saved as a consequence of modern neonatal intensive care procedures.⁷⁰ While surgery is successful in correcting life-threatening cardiac and intestinal defects which are commonly associated with Down's Syndrome, the same surgical gift cannot alter mental retardation which also is caused by Down's Syndrome.⁷¹

The Sheffield Standards

A study conducted in the early 1970s at Children's Hospital in Sheffield, England provides another set of guidelines for determining when care may be withheld from handicapped infants.⁷² The Sheffield study focused on the presence of those conditions that dictate whether the infant will either die early, regardless of the care given, or suffer severe multi-system handicaps that preclude the child from living an independent, dignified life or enjoying meaningful interpersonal relations. The following conditions were found to merit the withholding of treatment:

1. Thoracolumbar or thoracolumbosacral lesion (lesion on the thoracic and lumbar parts of the spine);
2. Gross paralysis of the legs with a neurologic segmental level below the third lumbar;
3. Kyphosis or scoliosis (abnormal curvature of vertebral column);
4. Gross hydrocephalus (accumulation of fluid within the brain)

67. Young, *supra* note 55, at 15.

68. *Id.*

69. American Academy of Pediatrics v. Heckler, 561 F. Supp. 395, 396 n.2 (D.D.C. 1983).

70. *Id.*

71. *Id.*

72. John Lorber, *Early Results of Selective Treatment of Spina Bifida Cystica*, 4 BRIT. MED. J. 201 (1973).

with a head circumference at least two centimeters above the ninetyieth percentile related to birth weight;

5. Intracerebral (brain) birth injury; and

6. Other gross congenital defects, such as cyanotic heart disease (cardiac malformation causing insufficient oxygenation of the blood).⁷³

IV. THE OKLAHOMA EXPERIMENT AND STANDARDS

A five year experiment studying sixty-nine infants was undertaken by the Departments of Orthopaedic Surgery, Pediatrics, Neurosurgery, and Urology at the University of Oklahoma Health Sciences Center, together with the staff of the Department of Social Service at the Oklahoma Children's Memorial Hospital in Oklahoma City.⁷⁴ When the study was published in October 1983, it focused renewed attention and concern over the standards for treatment and non-treatment of defective newborns. Essentially, the authors of the study concluded that six criteria were used to determine whether vigorous treatment or support care (*i.e.*, no active treatment) of infants born with myelomeningocele was to be given.⁷⁵ Their conclusions were based upon a 1974 study undertaken to determine when treatment should be given to infants with low capacity for intellectual development.⁷⁶ The criteria consisted of:

1. A frontal cerebral mantle greater than 1.0 cm. or brain mass greater than 60% mean for age;
2. An absence of a systemic disorder that could cause hydrocephalus and severe brain malfunction;
3. An absence of roentgenographic and neurologic signs of severe brain deformity;
4. An absence of noteworthy CNS [central nervous system] bleeding and infection;
5. An absence of major malformations that would preclude self-care as an adult; and
6. A family with economic and intellectual resources who lived

73. *Id.* at app.

74. Richard H. Gross et al., *Early Management and Decision Making for the Treatment of Myelomeningocele*, 72 PEDIATRICS 450 (1983).

75. *Id.* at 451.

76. David B. Shurtleff et al., *Myelodysplasia: Decision for Death or Disability*, 291 NEW ENG. J. MED. 1005 (1974). An infant quality-of-life study by Dr. Anthony Shaw was also factored into the conclusions. See Anthony Shaw, *Defining the Quality of Life*, HASTINGS CENTER REP., Oct. 1977, at 11. For additional guidelines within which physicians may evaluate an individual's permanent impairment resulting from dysfunction of the brain, spinal cord, and cranial nerves, see GUIDES TO THE EVALUATION OF PERMANENT IMPAIRMENT (Alan Engleberg ed., 1988).

within reach of an appropriate medical facility, or a commitment by a social agency to provide needed resources such as a foster home or medical care costs.⁷⁷

The myelomeningocele "team" at the University of Oklahoma Health Science Center, rather than the parents of the handicapped infants, made the ultimate recommendation for "supportive care" for thirty-three of the sixty-nine defective newborns studied.⁷⁸ Efforts were sought to involve the federal government, specifically the Department of Health and Human Services and the Justice Department, to investigate the Oklahoma practice and determine whether a violation of Section 504 of the Federal Rehabilitation Act had occurred, but no federal investigation was mounted.⁷⁹

Disputations of Civil Rights

The United States Civil Rights Commission issued a report on September 22, 1989, which asserted that possibly hundreds of cases existed where children born with severe disabilities were continuing to be denied adequate medical treatment, violating federal anti-discrimination laws designed to prevent this very conduct.⁸⁰ However, no actual documentation of these cases was given by the Commission and the report itself was the subject of intense debate within the Commission regarding the propriety and validity of its conclusions.⁸¹

The Executive Director of the American Academy of Pediatrics disputed the accuracy of the major conclusion of the Commission's report concerning infant discrimination and asserted "most pediatricians and neonatologists would probably advocate providing more treatment rather than discontinuing it for severely disabled newborns."⁸² He observed further that recently created infant care review committees, together with new federal and state regulations in the area, will combine to safeguard the defective newborn's equal treatment.⁸³

77. Gross et al., *supra* note 74, at 451.

78. *Id.* at 452; *see also* Thompson, *supra* note 52, at 81-82 (discussing similar decisions by medical teams in France).

79. Martin H. Gerry, *The Civil Rights of Handicapped Infants: An Oklahoma "Experiment,"* 1 ISSUES L. & MED. 15, 56-59 (1985).

80. U.S. COMM'N ON CIVIL RIGHTS, MEDICAL DISCRIMINATION AGAINST CHILDREN WITH DISABILITIES (1989); *see also* Julie Johnson, *Rights Panel is Critical of Care of Disabled Newborns*, N.Y. TIMES, Sept. 23, 1989, at 8 (presenting reactions to the Commission's report).

81. Johnson, *supra* note 80.

82. *Id.* at 8.

83. *Id.*

V. A BRITISH CASE-IN-POINT

The Plight of Baby C

On December 23, 1988, in Yorkshire, England, a baby girl weighing five and one-half pounds was born five weeks premature with a more serious than usual form of hydrocephalus, thereby causing her head to swell excessively and damaging the brain's vital cortex area. She was blind and deaf, with minimal growth of her limbs. Mr. Justice Ward, sitting in the Family Division of the High Court, likened her to a "foetus."⁸⁴ "Baby C" had to be fed by a syringe every four hours; during a six to eight hour cycle of feeding each day she would consume only twelve teaspoons of milk. With the full consent of the infant's parents, the attending physicians petitioned Justice Ward to rule that measures to prolong the baby's life be abandoned. The judge agreed with the physicians on April 17, 1989 and ordered the baby "treated to die" (e.g., denied nutrition).⁸⁵ The British Medical Association concurred with the court's ruling and maintained that such a decision should *not* be made unilaterally by the attending physicians.⁸⁶

An appeal was taken by David Venables, the Official Solicitor appointed as the infant's legal guardian (as the child was made a ward of the court), to the Court of Appeal on April 20, 1989 and heard before Lord Donaldson of Lynton, Master of the Rolls, Lord Justice Balcombe, and Lord Justice Nicholls. The following day, the Lords modified part of the order given by Mr. Justice Ward by directing that Baby C was no longer "to be treated to die" and thus was to be fed.⁸⁷ The Lords also directed that the physicians in charge decide upon the most appropriate manner to allow the terminal infant to die with a semblance of dignity and compassion.⁸⁸

Describing the decision—which mandates the mode of "treatment" that makes the infant as comfortable as possible but does not seek to prolong her life—as an "awesome responsibility,"⁸⁹ Lord Donaldson stated that the "paramount interest of the ward's welfare" was the standard by which a

84. David Cross, *Judge Allows Brain-Injury Baby to Die*, THE TIMES (London), Apr. 17, 1989, at 9; see H. TRISTAM ENGLEHARDT, JR., THE FOUNDATIONS OF BIOETHICS 202-49 (1986) (discussing the many factors that go into the consideration to "treat an infant to die," including, but not limited to, the doctor's opinion, the quality and length of life, and the burdens upon the family and society).

85. David Nicholson-Lord, *Child Can Be Allowed to Die, Judge Says*, THE TIMES (London), Apr. 21, 1989, at 3.

86. See Cross, *supra* note 84.

87. Nicholson-Lord, *supra* note 85, at 3. Lord Donaldson actually gave a two-part decision in this case: the first on April 20, 1989, and the second on April 26, 1989. An edited transcript of his opinions is found in 139 NEW L.J. 612, 612-14 (1989).

88. Nicholson-Lord, *supra* note 85, at 3.

89. *Id.*

judicial decision should be made consistent with prevailing medical opinion in the case that "the goal of treatment was to ease suffering, rather than achieve a short prolongation of life."⁹⁰ He stressed that in decisions of this nature, a *balance* should always be sought "between short-term gain and needless prolongation of life."⁹¹

In order to maintain the privacy of Baby C and her family and prevent public intrusion, Justice Ward originally issued two injunctions that were sustained by the Court of Appeal.⁹² The first injunction prevented inquiry into the identity of the infant, its parents, the local authority, the local health authority, or the hospital, physicians, and staff involved with Baby C; the other injunction restrained "the media by itself, servants, agents or otherwise from publishing any material which will identify or assist in identifying any of the persons or bodies" in the previous or in the first injunction.⁹³

This "ring of protection" is a most insightful and humane judicial posture—one to be applauded *and* duplicated in all right-to-die cases, whether the subjects are defective newborns⁹⁴ or terminally ill adults seeking their protected right of autonomy or self-determination.⁹⁵ All too sadly in America, an inquisitive, unsophisticated press intrudes—with often tragic consequences—into the individual and family decision-making processes. These intrusions must stop if private, dignified, and compassionate resolutions of right-to-die cases are to be the standard; such intrusions should not require court imposed sanctions or other judicial intervention.⁹⁶

VI. FEDERAL RIGHTS, STATES RIGHTS, AND THE SUPREME COURT

On June 9, 1986, Justice John Paul Stevens held that federal regulations, which were promulgated under Section 504 of the Federal Rehabilitation Act of 1973 and designed to prevent hospital discrimination in the care of handicapped newborns, were invalid and, thus, not authorized by the Act

90. *Treatment to Ease Pain Rather than Prolong Life*, THE TIMES (London), Apr. 21, 1989, at 36 [hereinafter *Treatment to Ease Pain*].

91. *Id.*; see also Margery W. Shaw, *When Does Treatment Constitute a Harm?*, in EUTHANASIA AND THE NEWBORN (Richard C. McMillan et al. eds., 1986) (identifying and discussing some of the sociological and scientific elements that contribute to the treatment, or withholding of treatment, of seriously defective newborns).

92. *Treatment to Ease Pain*, *supra* note 90, at 36.

93. *Id.*

94. See Smith, *supra* note 6. See generally Sinclair, *High Technology, High Costs and The Very Low Birth-Weight Newborn*, in EUTHANASIA AND THE NEWBORN (Richard C. McMillan et al. eds., 1986).

95. George P. Smith, II, *All's Well That Ends Well: Toward a Policy of Assisted Rational Suicide or Merely Enlightened Self-Determination*, 22 U.C. DAVIS L. REV. 275, 336 (1989).

96. See generally GEORGE P. SMITH, II, *FINAL CHOICES: AUTONOMY IN HEALTH CARE DECISIONS* (1989); I. KENNEDY, *TREAT ME RIGHT* 15, 15-17 (1988).

itself.⁹⁷ The Court accepted the argument proposed by this author in an *amicus curiae* brief in this case, asserting that causes of action designed to prevent the discrimination of defective newborns were traditionally relegated to state law in an area that is basically the concern of the state—namely the prevention of child abuse.⁹⁸ Indeed, each of the fifty states and the District of Columbia have enacted legislation designed specifically to provide for a duty to report,⁹⁹ thus allowing the state to investigate,¹⁰⁰ assign custody,¹⁰¹ and prosecute¹⁰² incidents of child abuse. The Section 504 regulations were accordingly held by the Supreme Court to be duplicative, unnecessary, redundant, and intrusive into the inherent rights of the states.¹⁰³ Nevertheless, some physicians have asserted that “the Child Abuse and Neglect and the Discrimination Against the Handicapped Statutes, as amended to bolster the Baby Doe Regulations, serve to inhibit decisions to stop treatment once it has been initiated, even when beneficence is not possible, nonmaleficence is being breached, and justice is not being served.”¹⁰⁴

Federal Intrusions

The pertinent part of the Child Abuse Amendments of 1984,¹⁰⁵ as they

97. *Bowen v. American Hosp. Ass'n* 476 U.S. 610, 647 (1986). *But see* Steven R. Smith, *Disabled Newborns and the Federal Child Abuse Amendments: Tenuous Protection*, 37 *HASTINGS L.J.* 765 (1986).

98. Brief of *Amicus curiae*, *Bowen v. American Hosp. Ass'n*, 476 U.S. 610 (1986) (on file with THE JOURNAL OF CONTEMPORARY HEALTH LAW AND POLICY at The Columbus School of Law, The Catholic University of America).

99. *See, e.g.*, ARIZ. REV. STAT. ANN. § 13-3620 (1989); FLA. STAT. ANN. § 415.504 (West 1986); GA. CODE ANN. § 49-5-183 (Michie 1990); HAW. REV. STAT. § 350-1.1 (1988); IND. CODE ANN. § 31-6-11-3 (Burns 1987); MICH. COMP. LAWS ANN. § 722.623 (West 1968 & Supp. 1991); MINN. STAT. ANN. § 626.556 (West 1983 & Supp. 1991); MO. ANN. STAT. § 210.115 (Vernon 1983); NEB. REV. STAT. § 28-711 (1989); N.Y. SOC. SERV. LAW § 413 (Consol. 1984); R.I. GEN. LAWS § 40-11-3 (1990); S.D. CODIFIED LAWS ANN. § 26-10-10 (1984).

100. *See, e.g.*, D.C. CODE ANN. § 6-2104 (1989); MONT. CODE ANN. § 41-3-202 (1989); NEV. REV. STAT. ANN. § 432B.260 (Michie 1986); N.D. CENT. CODE § 25.1-05 (1989); ORE. REV. STAT. § 418.747 (1989); TEX. FAM. CODE ANN. § 34.05 (West 1986).

101. *See, e.g.*, IDAHO CODE § 16-1613 (1979 & Supp. 1991); PA. STAT. ANN. tit. 11, § 23 (1965); TENN. CODE ANN. § 37-1-404 (1984); VA. CODE ANN. § 63.1-248.9 (Michie 1987); WASH. REV. CODE ANN. § 26.44.056 (West 1986).

102. *See, e.g.* ALA. CODE § 26-15-3 (1986); COLO. REV. STAT. § 18-6-401 (1986 & Supp. 1990); ILL. ANN. STAT. ch. 23, para. 2368 (Smith-Hurd 1988); LA. REV. STAT. ANN. § 14:93 (West 1986); ME. REV. STAT. ANN. tit. 19, § 218 (West 1981); MD. ANN. CODE art 27, § 35A (1987 & Supp. 1990); N.M. STAT. ANN. § 30-6-1 (Michie 1978 & Supp. 1991); N.C. GEN. STAT. § 14-318.4 (1986); OKLA. STAT. ANN. tit. 21, § 843 (West 1983 & Supp. 1991); UTAH CODE ANN. § 76-5-109 (1990); WIS. STAT. ANN. § 940.201 (West 1982).

103. *Bowen v. American Hosp. Ass'n*, 476 U.S. 610, 639-42.

104. Young & Stevenson, *supra* note 55, at 551.

105. 42 U.S.C. §§ 5101-03 (1988).

relate to defective newborns, structures a framework for medical care and treatment.¹⁰⁶ Under these regulations, beneficial medical treatment must be provided by hospitals receiving federal grant assistance to any infant unless: it is chronically and irreversibly comatose; providing for such treatment would merely prolong dying or otherwise be futile in terms of the infant's survival; or the treatment itself would, under the particular facts of the case in question, be considered inhumane.¹⁰⁷ The codified regulations state specifically that even under these exceptions, a patient cannot be denied "appropriate nutrition, hydration, and medication."¹⁰⁸ It has been suggested that this standard provides a workable foundation for the development of a similar standard of care towards terminally ill adults.¹⁰⁹ Although regulations of this nature may be promulgated, it remains to be seen at what level of enforcement they are maintained and at what level of judicial cognizance they are given. Judicial interpretation and recognition are crucial to any long-term directional change in the jurisprudence of handicapped newborns.

Government involvement would be welcome *if* it were designed to decrease the number of premature infants born each year by increasing the funding for programs that provide food and prenatal care for expectant mothers. Indeed, there is general agreement among experts that the simplest and most direct way to effect financial savings is to advance sound prenatal care. In fact, it is calculated that for every dollar spent on a pregnant woman before delivery, a net savings of more than three dollars will be realized for medical expenses the average infant will incur during its first year of life.¹¹⁰

106. 45 C.F.R. § 1340.15 (1990). *See generally*, George P. Smith, II, *Defective Newborns and Government Intermeddling*, 25 MED. SCI. & L. 44 (1985) (asserting that there is no need for direct government involvement by way of federal regulatory scheme beyond the laws already in place protecting children from abuse); Kate H. Lind, Note, *Medical Treatment Decisionmaking for Seriously Handicapped Infants: Is There a Role for the Federal Government?*, 29 B.C. L. REV. 715 (1988) (exploring the changing role of the federal government in medical treatment decision-making for handicapped infants during the 1980s).

Currently, \$16.5 million in federal grant monies are allocated to state child abuse agencies to aid them in defining the extent of acts of withholding medical treatment which may qualify as medical neglect. State grant recipients are required to structure procedures that allow for these cases of neglect to be reported promptly to the designated child protection agencies, which are empowered to force medical treatment. Every state except California, Indiana, and Pennsylvania receives these grant monies. Sarah Glazer, *Whatever Happened to Baby Doe?*, WASH. POST, Apr. 2, 1991, Health Magazine, at 8, 12.

107. 45 C.F.R. § 1340.15(b)(2) (1990).

108. *Id.*

109. C. Everett Koop & Edward R. Grant, *The "Small Beginnings" of Euthanasia: Examining the Erosion in Legal Prohibitions Against Mercy-Killing*, 2 NOTRE DAME J.L. ETHICS & PUB. POL'Y 585 (1986).

110. Priscilla Painton, *Mere Millions for Kids*, TIME, Apr. 8, 1991, at 29. For financial

Coordinated state and federal legislative schemes which promote voluntary educational programs for genetic screening before marriage would also reduce the likelihood of handicapped infants being born. Federal regulation of contaminants and chemical pollutants could also reduce the incidence of genetic deformity. The federal government could establish an advisory task force responsible for promulgating guidelines which classify birth diseases and problems that merit medical treatment to a predetermined standard. There must be an unequivocal governmental policy that ensures that all handicapped individuals—regardless of age—will not be denied medical services on the basis of that handicap. An even more far-reaching position would be that legislatures recognize that no citizen—handicapped or otherwise—should be denied needed medical services because of an inability to pay.¹¹¹

A Contemporary Dilemma

James E. Strain, Executive Director of the American Academy of Pediatrics, acknowledges that today the defective newborn is treated more aggressively than in the 1970s and early 1980s.¹¹² Two decades ago, for example, sixty percent of infants born with spina bifida survived; today more than ninety percent do.¹¹³ These dramatic survival rates are attributed to a growing social acceptance of severely handicapped newborns, thereby promoting medical philosophies which mandate aggressive treatment.¹¹⁴ Indeed, contemporary neonatologists and pediatric surgeons show a growing commitment to treatment as opposed to nontreatment.¹¹⁵ Yet, this new trend toward advancing treatment of all hopelessly ill newborns is considered to be flawed both medically and morally because of the high emotional and economic harm inflicted upon those who survive as well as the great financial burden placed upon health care maintenance facilities and society at large in maintaining the handicapped infants.¹¹⁶

statistics on the annual cost of neonatal intensive care, see Young & Stevenson, *supra* note 55, at 549-50.

111. George J. Annas, *Disconnecting the Baby Doe Hotline*, HASTINGS CENTER REP., June 1983, at 14, 16. For a proposal that hospital and pediatric ethics committees serve in an advisory capacity in decisions involving life-prolonging medical treatment, see generally George P. Smith, II, *The Ethics of Ethics Committees*, 6 J. CONTEMP. HEALTH L. & POL'Y 157 (1990); Robert F. Weir, *Pediatric Ethics Committees: Ethical Advisers or Legal Watchdogs?*, 15 LAW MED. & HEALTH CARE 99 (1987).

112. Glazer, *supra* note 106, at 8.

113. *Id.* at 13.

114. *Id.*

115. *Id.* at 12.

116. *Id.* at 8.

The American Academy of Pediatrics Responds

In September 1986, a questionnaire was sent to 1007 members of the Perinatal Pediatrics Section of the American Academy of Pediatrics that was designed to elicit their views regarding the two sets of Baby Doe regulations:¹¹⁷ those promulgated under the Child Abuse Amendments of 1984,¹¹⁸ and those promulgated under Section 504 of the Federal Rehabilitation Act of 1973 that were struck down subsequently by the Supreme Court on June 9, 1986, in *Bowen*.¹¹⁹ The survey sought information from the physicians regarding their views of the effect these regulations were having on their practice. Four hundred ninety-four members (or forty-nine percent) of the Academy responded.¹²⁰

The tabulation of the questionnaire revealed that seventy-six percent of the respondents were of the opinion that the current regulations are not necessary to protect the rights of defective newborns, with sixty-six percent expressing their belief that the regulations are an interference with parental autonomy to chart what was in their children's best interests, and another sixty percent believed the regulations do not adequately consider infants' suffering.¹²¹ Fifty-six percent of the neonatologists thought that even when chances for survival of critically ill patients were very poor, over-treatment was administered.¹²² Thirteen percent were uncertain about this conclusion, and thirty-one percent disagreed totally.¹²³ Interestingly, over four-fifths of the respondents expressed their belief that if the federal government mandated intensive life-saving treatment for defective newborns, it should in turn guarantee payment for all subsequent treatments.¹²⁴

A New Government Direction?

Over time, the Americans with Disabilities Act of 1990¹²⁵ may have a significant impact on health care delivery for the disabled. While providing little guidance for regulating medical decision-making, other than requiring equal access and integrated facilities for the disabled, section 302(b)(2)(1) of the Act appears to permit physicians to continue to refuse to offer treatments

117. Loretta Kopelman et al., *Neonatologists Judge the "Baby Doe" Regulations*, 318 NEW. ENG. J. MED. 677, 677 (1988).

118. 42 U.S.C. §§ 5101-03 (1988); see also *supra* notes 106-08.

119. 476 U.S. 610 (1986); see also *supra* note 103.

120. Kopelman et al., *supra* note 117, at 677.

121. *Id.* at 679.

122. *Id.*

123. *Id.*

124. *Id.*

125. Pub. L. No. 101-336, §§ 1-3, 104 Stat. 327 (1990).

which are not in the patient's own best interests.¹²⁶ The specific provision prohibiting treatment that is "different or separate from that provided to other individuals, unless such action is necessary to provide the individual or class of individuals with a good, service . . . or other opportunity that is as effective as that provided to others,"¹²⁷ may force a change in the directional focus of lower courts, for there is a growing reluctance to hold that medical decisions are discriminatory when the questioned disability is found interacting with another condition, thereby complicating medical treatment.¹²⁸

Exaggerated Fears of Euthanasia?

Even though there may be a statutory base for protecting terminally ill infants and adults from selective nontreatment, a variety of judicial rulings,¹²⁹ starting with the famous Karen Quinlan case,¹³⁰ has begun to recognize a right to die and has given it constitutional protection.¹³¹ Some commentators assert that if a guardian is given the means to stipulate the incompetent patient's desire to die, then all persons would have a right to receive "voluntary" euthanasia—whether or not they actually request it.¹³² *Quinlan* provides a framework in which the legalization of voluntary euthanasia will inevitably lead to the generalized practice of all forms of euthanasia.¹³³

126. See Wendy E. Parmet, *Discriminations and Disability: The Challenges of the ADA*, 18 LAW MED. & HEALTH CARE 331, 339 (1990).

127. Americans with Disabilities Act § 302(b)(1)(A)(iii).

128. Parmet, *supra* note 126, at 339.

129. See, e.g., *Bartling v. Superior Court*, 209 Cal. Rptr. 220 (Ct. App. 1984); *Barber v. Superior Court*, 195 Cal. Rptr. 484 (Ct. App. 1983); *John F. Kennedy Memorial Hosp. v. Bludworth*, 452 So. 2d 921 (Fla. 1984). But see *In re Westchester County Medical Center*, 531 N.E.2d 607 (N.Y. 1988), where the New York Court of Appeals held that inserting a nasogastric tube in a 77-year-old widow who was severely debilitated from a series of strokes was legally required, thus providing her with nutrition and hydration. For a related view, see *Cruzan v. Harmon*, 760 S.W.2d 408 (Mo. 1988) (en banc), cert. granted sub nom. *Cruzan v. Director, Mo. Dep't of Health*, 492 U.S. 917, 917 (1989), in which the Missouri Supreme Court held that a state's interest in life outweighed a vegetative patient's right to terminate artificial sustenance. The Supreme Court agreed in *Cruzan v. Director, Mo. Dep't of Health*, 110 S.Ct. 2841 (1990), and found that it was proper for the state to apply a clear and convincing standard of evidentiary proof in determining an incompetent patient's right, exercised through a guardian, to discontinue nutrition and hydration when condemned to live in a persistent vegetative state. *Id.* at 2854.

130. *In re Quinlan*, 355 A.2d 647 (N.J. 1976), cert. denied sub nom. *Garger v. New Jersey*, 429 U.S. 422 (1976).

131. *Koop & Grant*, *supra* note 109, at 621.

132. *Id.*

133. *Id.* During the 1st Session of the 100th Congress, H.R. Con. Res. 194 was introduced on October 7, 1987, calling for an expression by the Congress of its sense "that efforts to allow people to assist others to commit suicide and efforts to promote suicide as a rational solution to

Similarly, in disclaiming the growing popularity of voluntary euthanasia, one author cautions that,

judicial authorization of third-party judgments that rest on express statements to the effect that those with severe handicaps "never lead very good lives," that they are "better off dead," or that their right to equal treatment should depend on the "economic, emotional and marital effects on the[ir] family as a whole," is an open invitation to the making of legal policy . . . based on "irrational prejudices."¹³⁴

The author further asserts that the law has regressed to the point where it is arguably legal to authorize active steps to end a person's life solely because he is disabled.¹³⁵

CONCLUSION

Contrary to commonly held beliefs,¹³⁶ the law is progressing—not regressing—in acknowledging more rights of self-determination, humanness, love, and principled adherence to long recognized and tested principles of *triage*¹³⁷ and realizing that cost-benefit analysis is a proper consideration in health care management decisions.¹³⁸ Thus viewed, acts of selective non-

certain problems should be opposed." See also, *Bernardin Condemns Legal Assisted Suicides*, WASH. POST, Feb. 20, 1988, at C6 (expressing fears that the resolution will make it legal to help others commit suicide). For comparative studies on perceptions of euthanasia, see K.M. Sharma, *Euthanasia in Australasia*, 2 J. CONTEMP. HEALTH L. & POL'Y 131 (1986) (comparing the U.S. and Australasia); George P. Smith, II, *Re-Thinking Euthanasia and Death with Dignity: A Transnational Challenge*, 12 ADEL. L. REV. 480 (1990) (comparing the U.S. and Australia); Henk Rigter, *Euthanasia in the Netherlands: Distinguishing Facts from Fiction*, HASTINGS CENTER REP., Jan.-Feb. 1989, at 31 (comparing the U.S. and the Netherlands).

134. Robert A. Destro, *Quality-of-Life Ethics and Constitutional Jurisprudence: The Demise of Natural Rights and Equal Protection for the Disabled and Incompetent*, 2 J. CONTEMP. HEALTH L. & POL'Y 71, 115 (1986) (quoting *American Academy of Pediatrics v. Heckler*, 561 F. Supp. 395, 400 (D.D.C. 1983)).

135. *Id.* at 127.

136. See, e.g., *supra* notes 134-35 and accompanying text.

137. Triage is defined as

Medical screening of patients to determine their relative priority for treatment; the separation of a large number of casualties, in military or civilian medical care, into three groups: 1) those who cannot be expected to survive even with treatment; 2) those who will recover without treatment; 3) the highest priority group of those who need treatment in order to survive.

STEDMAN'S MEDICAL DICTIONARY 1628 (25th ed. 1990). See generally George P. Smith, II, *Triage: Endgame Realities*, 1 J. CONTEMP. HEALTH L. & POL'Y 143 (1985) (applying the concept of triage to decisions involving life-sustaining treatment).

138. Rosemary Donley, *A Brave New World of Health Care*, 2 J. CONTEMP. HEALTH L. & POL'Y 47, 51 (1986); see also Edmund D. Pellegrino, *Rationing Health Care: The Ethics of Gatekeeping*, 2 J. CONTEMP. HEALTH L. & POL'Y 23 (1986) (questioning the physician's duties to both society and patients with respect to health care expenditures).

treatment can never be considered as acts of murder but rather as courageous acts of more humane and enlightened kindness, or even love.

